TESTING TREATMENTS

DON'T PLAY POKER WITH YOUR GENES

'Acting on the knowledge of a single (or even a few) gene variants is similar to betting all your money on a poker hand when you've only seen one card. You don't know what hand genetic factors has dealt you, nor what effects your environment will have, and here, instead of 5 cards, there are over 20,000 genes and many thousands of environmental factors. And the effect of one gene may be cancelled out by the effect of lifestyle, family history or by the presence of other, protective genes. Many of us carry faulty genes without them ever causing disease.'

Sense About Science. *Making sense of testing: a guide to why scans and other health tests for well people aren't always a good idea*. London: Sense About Science 2008, p7. Available from www.senseaboutscience.org

about your risk of disease, let alone what might be done about it, if anything. This 'do-it-yourself' approach clearly does not meet the criteria for a useful screening test (see below). However, the result may well make you anxious and decision-making difficult, and may have wider implications too – on members of your family, for example. As one Australian health journalist put it 'For anyone concerned about the creeping medicalisation of life, the marketplace for genetic testing is surely one of the latest frontiers, where apparently harmless technology can help mutate healthy people into fearful patients, their personhood redefined by multiple genetic predispositions for disease and early death.'[20]

What screening aims to achieve and why evidence matters

The examples we have already given show that, before rushing headlong into widespread screening, it is worth pausing a moment to consider the key features of screening programmes and to remind ourselves what they aim to achieve. People being offered screening do not have, or have not noticed, the symptoms or signs of the condition being tested for – they have not sought medical attention for the disorder in question. The purpose of screening

individuals or populations is to reduce the risk of death or future ill health from a specific condition by offering a test intended to help identify people who could benefit from treatment.[1, 21] The aim of screening is not simply to diagnose disease earlier – this may not help anyone and it can even do harm.

The basic criteria for assessing the value of screening tests were outlined in a World Health Organization report in 1968.[22] These criteria have been further refined to reflect the way in which healthcare is delivered today. People invited for screening need sufficient, balanced information about the test being offered – including possible harms, consequences, and limitations, as well as potential benefits – so that they can make an informed choice. Essentially, the key points can be summed up by saying don't screen unless:

- The condition being screened for is important in terms of public health – for example, it is serious and/or affects large numbers of people
- There is a recognizable early stage of the condition
- There is an effective and acceptable treatment for the condition, so screening is likely to make a difference to its outcome
- There is a valid and reliable test for the condition that is acceptable to people being offered screening
- The screening programme is of good quality and cost-effective in the setting in which it is to be offered
- The information provided to people is unbiased; based on good evidence; and clear about possible harms (eg, overdiagnosis leading to over-treatment) as well as potential benefits
- The invitation for screening is not coercive – that is, it indicates it is reasonable to decline
- The chance of physical or psychological harm to those offered screening is likely to be less than the chance of benefit
- There are adequate facilities for the diagnosis and treatment of abnormalities detected by screening

THE SCREENING CIRCUS

In 2009, a recently retired professor of neurology with a long-standing interest in stroke prevention learnt that neighbours had received a leafleted invitation to be screened for stroke and other complications of cardiovascular disease. The leaflet, from a vascular screening company, invited them to go along to a local church (and pay £152, $230, €170) for a series of tests. Intrigued – not least because some of the information in the leaflet was factually misleading – he decided to go along himself.

'First up was aortic aneurysm [enlargement of the main artery carrying blood from the heart] screening with ultrasonography done by a woman who did not want to be engaged in conversation about what the implications of finding an aneurysm might be. Next it was ankle and arm blood pressure measurements "for troubles with my circulation" . . . followed by a little non-vascular bonus: osteoporosis screening of my ankle. Then there was . . . electrocardiography to detect "trouble with the two upper chambers of my heart" . . . Then, finally, carotid [artery in the neck] ultrasonography to detect "plaque build up". When I asked them what the implications of this might be they told me that blood clots could form and cause a stroke. Pressed on the sort of treatment I might be given, they offered a vague notion of blood thinning drugs but nothing about surgery until I asked directly if that might be an option, and indeed it was. "Might that be risky?" I enquired innocently. The answer was that any risks would depend on a full work-up by my GP, with whom I should discuss abnormalities from any of the tests.

All of this was conducted without any privacy (except for the aortic aneurysm screening) . . . There seemed to be no doctor present, and the team showed no intention or will to engage in a discussion of the implications of false positive or false negative results, the prognostic implications of true abnormalities, or the risks and benefits of any treatments.

> This was just screening, nothing more and nothing less, done for profit – with the results to be dumped in my lap within 21 working days and for my GP to sort out the emotional and physical consequences of any abnormality, true or false, even though she didn't request the tests. . . . Inevitably this whole screening circus is liable to whip up anxiety in vulnerable people without discussing or taking the slightest responsibility for the consequences of any abnormalities found.'
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> Warlow C. The new religion: screening at your parish church. *BMJ* 2009;338:b1940

These criteria reinforce our message at the beginning of this chapter: that any decision to introduce a screening programme should be based on good-quality evidence not only about its effectiveness but also about its potential for doing harm.

IS ANYONE NORMAL?

Whole-body CT scans

Among the tests on offer at private clinics are whole-body computed tomography (CT) scans to look at head, neck, chest, abdomen, and pelvis. They are offered directly to the public, and usually done without reference to the person's general/primary care practitioner. Whole-body scans are often promoted as the way to keep one step ahead of possible illness, with the premise that a 'normal' result will be reassuring. Not only are these scans expensive, but also there is no evidence that any overall health benefit is achieved by doing these tests in people without symptoms or signs of disease.

Moreover, the radiation exposure is considerable – as much as 400 times more than a chest X-ray. So much so that in 2007 the UK's Committee on Medical Aspects of Radiation in the Environment (COMARE) strongly recommended that 'services' offering whole-body CT screening of asymptomatic individuals